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ABSTRACT

This paper presents a compendium developed as a result of a series of seminars held during 1988 to commemorate the 350th anniversary of the first Swedish colony in North America. The seminar of which this is a follow-up was specifically focused on people with disabilities. It consists of interviews with four prominent Swedish and American experts in public policy and special education: Sarah deVincentis, Martin Soder, Agneta Hellstrom, and Ann Turnbull. Topics discussed include: origins of national approaches to welfare needs, formation of social policy and social services systems, the roles of private and corporate philanthropy, effects of national economic prosperity on social conscience, projections for future trends, effects on families of social policy, parental advocacy and legislation. (PB)

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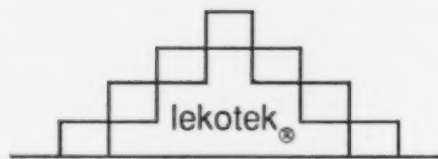
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THE FUNCTION OF CULTURE IN THE DEVELOPMENT OF SOCIAL POLICY



The following compendium was developed as a result of a
series of seminars held during 1988 to commemorate the 350th
anniversary of the first Swedish colony in North

America. The seminars were sponsored by:

Swedish Information Service

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International Relations Committee of

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INTRODUCTION

The year 1988 marked the 350th anniversary of the founding of the first Swedish colony in North America. In 1638, the first Swedish colonists arrived on the shores of the Delaware River. This was the culmination of many years of preparation, and the beginning of a long and productive presence in America.

To celebrate the mutual friendship and respect shared between the United States of America and Sweden, the year 1988 was designated by the United States Congress as the "Year of New Sweden." Throughout the next twelve months, a variety of events took place that provided millions of people with a unique look at Swedish culture, industry, technology and contemporary life. The purpose of the celebration was to increase the understanding of the partnership between the two nations.

As part of "New Sweden," a series of seminars were held to advance the dialogue between Swedish and American scholars on problems---and possible solutions---of vital concern to both nations. The following compendium was written as a follow-up to a seminar that was specifically focused on people with disabilities. The seminar was titled "The Function of Culture In The Development Of Social Policy." It was held in Evanston, Illinois and Washington, D.C. during the Spring of 1988. The participants were Mårten Söder, Inger Wästberg, Agneta Hellström, Irving Lazar, Ann Turnbull, Robert Silverstein and myself.

The sponsoring organizations for these seminars were the Swedish Information Service, the National Lekotek Center and the International Relations Committee of The Council for Exceptional Children. Speaking for the National Lekotek Center, we were very proud to be part of this project, particularly since we have our roots in Scandinavia.

The National Lekotek Center, located in Evanston, Illinois, was the first Lekotek established in the USA. It was begun in 1980 by a group of Chicago area educators, therapists and parents of children with disabilities.

Lekoteks are world-wide resource and support centers for families with children who have handicaps. The first Lekotek was begun in Sweden to provide families with home based alternatives to institutionalization. The mission of all Lekoteks is the integration of children with handicaps into the mainstream of society. To achieve this ambitious goal, Lekoteks provide parents with the practical help they need to care for their children. This includes family counseling, home loan of materials and equipment, support groups, school integration programming and access to adaptive microcomputers. Children coming to Lekotek have such disabilities as cerebral palsy, Down Syndrome, sensory disabilities, and long term illnesses, but really Lekoteks see only two kinds of children...boys and girls.

There are now more than 50 Lekoteks in the United States serving over 3,000 children and families. In addition to the established centers, there are presently 50 new sites in some stage of development. All of this growth has happened in less than nine years. This rapid expansion is a direct result of changing times, new opportunities for people with disabilities and a deep commitment by individuals and organizations in both Sweden and the United States of America. The success of Lekotek is an example of the benefits derived from a mutual sharing and respect between these two nations.

The National Lekotek Center is pleased to have been part of celebrating "New Sweden." We would like to particularly acknowledge the generous and professional assistance given to our agency by the Swedish Information Service. Because of their knowledge and experience this series of seminars and the following compendium have been an exciting and rewarding undertaking. In addition to the increased understanding gained from this project, we at Lekotek have had the unique pleasure of meeting some very special people.

In closing, let me mention a few of the many people and organizations who have helped to make this project a success. Karin Palmquist, Margareta Sjolund, Marta Feldt, Solveig Linka, Margareta Taterman, Majt Bostrum, Lisen Muldig, Barbara White, Miriam S. Harris, Judith Bondurant-Utz, Thelma Watkins, Harriet Ljungkvist Bagdade, the women of the Chicago branch of SVEA, the Council of Exceptional Children and, of course, our learned seminar participants. Thank you for giving so generously of your time and encouragement. This project is an example of what can be accomplished through a mutual sharing of ideas, experience and commitment to improving peoples' lives.

Sarah deVincentis
Executive Director
National Lekotek Center

Sarah deVincentis

Sarah deVincentis is Executive Director of the National Lekotek Center in Evanston, Illinois. With an extensive background in special education, she founded this charitable, nonprofit organization in 1980. She has testified before the Senate of the United States on the technological needs of children.

The United States of America has always had a private and pluralistic approach to general welfare needs. Can you explain the origins of these traditions?

To arrive at some understanding of the origins of the United States social policy, one needs to look back at the formative years of our country.

Before we were a nation of federated states, we were a group of thirteen separate colonies under England's rule. The first permanent English colony in the New World, Virginia, was established in 1607. During the next 250 years twelve additional colonies were begun along the eastern coast of what is now the United States of America. By the time of the Revolutionary War in 1774, these colonies had each developed its own strong social, religious and political cultures. It was only their shared opposition to the English monarchy that enabled them to join together as a unified force.

With the successful breaking away from England these thirteen, very diverse, colonies became one nation called the United States of America. Each state, however, retained its unique character and traditions. They looked to the federal government for very limited assistance in such areas as foreign policy, mail delivery and Indian matters.

For the next twenty-five years there was a struggle among the country's leaders as to the structure of power and government. Such leaders as John Adams and Alexander Hamilton sought to have a strong centralized government and proposed a model not so different from that of a monarchy. Their party, the Federalist Party, believed that powers wrested from the King and parliament should not be divided among thirteen states. Their efforts resulted in a strong constitution that had the genius of reconciling diversity with unity.

In 1801, the Federalist Party was defeated in the elections by Thomas Jefferson's party, the Republicans¹. The Federalists never again had the power to return to leadership. They left behind, however, a centralized administrative system that still serves our country well. The three branches of government - the executive, legislative and judicial - created during the time of the Federalist Party, remain today the core of our national system of government. In every aspect of our country's development one can see the effects of this balance of power. Perhaps, later in our conversation we can talk about the impact of these long ago developments on the present lives of people with disabilities.

The Republicans came into office believing they had saved the country from a return to monarchy. Their theory of government was based on an experiential understanding of an agrarian society. For this reason they deliberately moved away from a centralized government and to a more participatory form of rule. "Life, liberty and property values" became the virtues of Jefferson's party.

¹ The Republican Party (Republican Democratic) of Thomas Jefferson is not the same Republican Party that exists today. The present Republican Party was officially begun in 1854.

One of our country's greatest leaders and thinkers, Thomas Jefferson had a deep confidence and trust in the power of the individual. Unlike the Federalists, Jefferson believed that "all men are created equal." Under his administration states rights and democracy took on new meaning and life.

It is interesting to speculate what would have happened in our history had not Thomas Jefferson become president when he did or if the Federalist party had been able to maintain its leadership.

The commitment to states rights and the rights of the individual were underlying causes of the Revolutionary War and fundamental to our country's Constitution. In looking at today's public issues and policy decisions, these same themes create the tension and energy that drives our government forward.

How does this development of government and political theory affect the formation of social policy in the USA.

It is difficult to tie all the strings together, but I would like to mention a few circumstances that are particularly influential, but not always apparent.

Although several European countries were involved in the early colonization of the thirteen original colonies, it is predominantly English culture and traditions that have been adopted in this country. In the early English model, social needs were a responsibility of the Royal Family. Caring for the disadvantaged was an obligation of the nobility. Even today many charities in England take the name of a member of the royal family.

It was clear by the time that Jefferson became president that there would be no royalty in the new country, at least as defined by English standards. We did, however, develop our own royalty-like class of people. People in this rarefied level of society needed to have a large supply of money, but this in itself was not enough. Certain affectations were adopted from the English model. Having generations of money was helpful and so also was being publicly charitable.

Wealthy families would adopt a charitable cause and become its sponsor. Their name would often be associated with a specific charitable institution or organization. As time went by, this form of voluntary support proliferated. It filled a great need at a time when government was not involved in social or cultural services.

There were, however, some clear disadvantages to this unplanned response to public needs. It was based on the special interests of the sponsors and not necessarily on the level or degree of society's needs. Those geographic areas with the most wealthy families had the most access to services, which furthered the inequality among regions of this country. As sponsors proliferated so also did competition between charities. Popular causes might have several competing agencies within a very small area. On the other hand, unpopular causes might go dangerously underserved.

This form of charitable support set a pattern of service fragmentation that still exists today. Communities can have duplication of services to a particular group of people and have others in desperate need who are severely underserved.

Only in the 1980's has there been a strong trend to unify services through coalitions of competing agencies. This has been necessitated by severe budget cuts in public support to private agencies. For example, in the area of disabilities, it has been estimated that between 1980-88, there has been a 30% reduction of federal funding. Organizations representing various disability groups have found it effective, if not imperative, to join together as one voice to respond to this service and financial crisis. In the past, such groups as the Association for Retarded Citizens and the Council for Exceptional Children would be more likely to work independently of each other. It has taken a crisis situation to radically change entrenched patterns of service fragmentation and organizational competition. As to how strong these new coalitions and solidarity of effort will be, only time can tell.

Can you describe how or when public support to people with disabilities became a part of the social service system?

In 1929, with the crash of the world economy, it became clear that private charity in the USA was inadequate to meet the desperate needs of our society. Under Franklin Roosevelt the federal government was able to pass legislation to provide financial support to social services.

It is interesting to note that the first disability group to receive tax support was "crippled children." This group was included in the Social Security Act. There are two interesting pieces of trivia about the fact that "crippled children" was the first disability group to receive federal support. First of all, President Roosevelt, himself, was crippled by polio. President Roosevelt also was a member of our brand of "royalty," a man who came from a prominent and wealthy family. The beginning of federal support to disability issues has very distinct roots in the American system of responding to special interests.

The federal government became active in the issues of people with mental retardation under the administration of President John F. Kennedy. Again, it was a member of his family that gave him the motivation to seek improved services. President Kennedy was also a member of a wealthy and socially prominent family.

Throughout our history one can see these same recurring patterns that were established in the early years of our country's political system.

Federal policy is very dependent on special interests and the power of the individual. Responses by the federal government are fragmented and lack a central plan. From time to time there have been dedicated efforts at coordinating services. President Truman during his administration (1945-52) established the Department of Health, Education and Welfare with the intent to coordinate services to all areas of the country. President Johnson (1963-1970) launched the War on Poverty with the same intent. Both efforts have accomplished an improvement in the lives of thousands of our country's citizens, but have failed to provide a uniform standard of service throughout the United States. Regionalization, special interest lobbying and states rights still have a more powerful pull than the federal government's desire or ability to centralize services.

You mentioned a recent decline of public support to people with disabilities. Can you talk more about this development?

First of all, let me clarify what I mean by this recent change in public support to people with disabilities. There has been a significant diminution of federal support to programs for people with disabilities. This has necessitated a greater investment by state governments in this area of social service. Some states have successfully met this challenge with new and improved services, but other states have fallen further behind. Again we see this pattern of regionalization reinforced by federal policy.

The situation is complicated by the federal government mandate, through its legislative or judicial branches, that certain services must be provided to people. For example in 1986, P.L. 99-457 was passed. This federal law requires all states to provide early intervention services to children from birth to age five. Although the federal government does allocate some financial support, it is inadequate to cover all the costs mandated by this law. The states are obligated to make up the difference. Again, we feel the tension between states rights and the authority of the federal government.

What role has private charity had in meeting the present needs of the disadvantaged in the USA?

This country has a very unique system of private philanthropy. I believe it is unlike any other in the world. When the crash of 1929 necessitated the entry of the federal government into providing extensive social services, private philanthropy was not preempted, but rather it had a new partner.

In 1988, INDEPENDENT SECTOR² conducted a national survey on the giving and volunteering patterns of Americans. I think the results are quite illuminating in understanding the unique role that individuals play in supporting our system of services in the USA.

- * Over 80 million Americans or 45.3% of adults volunteered 4.7 hours per week in 1987. The estimated value of this volunteer effort represented the equivalent of 8.8 million employees at an estimated value of \$149.8 billion dollars.
- * Dollar contributions to charity exceeded \$100 billion in 1988.
- * People with incomes under \$10,000 gave 2.8% of what they had to charity. Those with \$10,000 to \$30,000 gave 2.5%. As the income went up families gave less of it to charity. The study clearly indicated that giving is not exclusive to people in higher incomes, but actually those with less are more generous.

Volunteerism and charitable giving are fundamental values in our society. As I mentioned earlier, these customs have strong roots in our adaptation of English cultural traditions. It is interesting to note, however, that as new immigrants have come to this country they also have enthusiastically adopted the American spirit of volunteerism and charitable giving. I believe there is something about American giving that corresponds to our value of an individual's freedom to choose how his/her money will be spent.

² INDEPENDENT SECTOR, Giving and Volunteering in The United States, Summary of Findings, (Washington, DC: INDEPENDENT SECTOR, 1988).

In recent years we have had major revisions of our tax policies, which have eliminated many tax benefits for charitable giving. Despite these disincentives, charitable giving in the United States by individuals continues to rise. Today 90% of private support is made up of contributions by individuals. Only about 10% of private support comes from corporations and foundations.

Speaking of corporate support, there has been much more interest in the role of corporations in the area of philanthropy and public policy. Can you talk a little about this growing involvement?

When President Reagan took office in 1980, it was an often expressed policy of his to seek a greater role for private philanthropy in meeting society's needs. He specifically targeted the business and corporate community.

Although it was impossible for private philanthropy to replace the funding lost through federal support, corporations did indeed take up the challenge. In each of the last eight years the percentage of corporate philanthropy has increased. Today it represents about a 4.5 billion dollar investment or 5% of the funding needed to run current programs. Indeed, corporate philanthropy has become big business in the 1980's.

This is a very interesting development that has some far-reaching implications. Let's consider the American Express campaign called "Hometown America" that occurred in the mid-1980's. For each purchase on an American Express card a percentage of money would be donated by American Express to selected charities. Here are some quick observations about this form of philanthropy that is quite unique to the USA and in truth to our present product marketing environment.

First of all, the campaign did benefit many people and a significant amount of money was raised for charitable purposes. It also heightened the public's awareness of the needs of others and the power of volunteerism. There are, however, some other interesting implications.

Has the corporate entity replaced the "prominent/royal family" in charitable giving? Would a corporation attach its name to a charity that met a need, but was not an appealing cause, for example, abused women? How often is the corporation's budget for philanthropy an extension of its public relations budget? If the corporation provides financial support, what control does it have over the policies of the recipient social service agency? How would this selective support affect the coordination of services regionally and nationally? Are the goals of corporate philanthropy and social service agencies the same? The answer to this last question seems "unlikely."

Corporate America has always played a role in forming social policy in the USA. In the past, however, it was often the conservative voice that warned against the dangers of providing social programs to the masses. Compulsory education and social security are two examples of basic programs originally opposed by corporate America. Today, there is a subtle change in the traditional conservative role that corporate America has always taken, perhaps as a result of Reagan politics that urges private interests to assume a greater responsibility for social programs.

Rather than distancing themselves from social programs, corporate leaders are taking an active role in seeking solutions to some of our greatest societal challenges. Urban revitalization, quality public education and universal health insurance are the major issues being addressed by corporate America. These are critical issues in the United States today that threaten the ability of American business to function efficiently.

It must, however, be clearly understood that the first responsibility of the corporation is not to the general welfare of the American public, but to its corporate stockholders. The role corporate America plays in the formation of social policy must always be understood in this context. It is foolish, if not reprehensible, for the government to depend on corporate leadership without understanding it is motivated by self-interest.

This year, 1989, the United States has a new president. It is still too early to know what impact President Bush will have on the direction of social policy. There is reason to be optimistic that he will address many of the social issues we have discussed here today. As a parent he has experienced the sorrow of having a child born with a disability, who died at a young age. He has many times characterized himself as "the education president" and has supported legislation that recognizes and strengthens family support systems.

President Bush, however, will have to work within a political system that was established long ago with the original constitution of 1786. In many ways he will face the same functional challenges as did Presidents John Adams and Thomas Jefferson. His presidency will require masterful balancing of the law, traditions, culture and interest groups that make up the unique American way of "getting the job done."

Mårten Söder

Mårten Söder is associate professor at the Department of Sociology, University of Uppsala, Sweden. He is currently engaged in a research program about "the social meaning of disability," investigating individual attitudes, professional theories and political ideologies in the field of disability.

Mårten Söder has acted as expert and consultant for UN and OECD. He is one of the founders of a newly established Center for Handicap Research at the University of Uppsala and scientific consultant for the Swedish National Board of Health and Social Welfare.

Sweden has always had a strong tradition of centralized public response to social welfare needs. Can you explain the roots of this tradition?

I think there are at least three important roots of the central response to social welfare that is an essential part of the Swedish model.

First of all, Sweden has a long tradition of strong central state-power. This dates back to the 16th century when Gustaf Vasa, Gustaf the First, freed us from the occupation of the Danish and established a central state. Through the use of army and bureaucracy he was able to co-opt the aristocracy and handle rebellious provinces. The central state thus created responded to the need of balancing different regions as well as handling clashing interests of rural classes and mobilizing resources for the defense against foreigners. Much of its success depended on the ability to balance those interests. The price the king had to pay was to allow the nobility to monopolize higher positions in the state. Thus, the King was not able to influence the everyday business of administration but had to govern through general guidelines and edicts.

This laid the basis for a rather unique Swedish characteristic of central government. Policy is made in rather small ministries where general guidelines and programs for social reforms are worked out. The implementation and evaluation of those programs, however, are entrusted to "ambetsverk"-- national boards for different policy-areas such as labor market, social affairs, and education. Routine bureaucratic activities are left to these boards, which are made up of civil servants who are appointed on grounds of professional competence rather than political commitment. This kind of division between political decision making by politically appointed civil servants in ministries and technical bureaucratic administration and implementation in our national boards is unique to Sweden and helps to explain the development of the Swedish model of the welfare state.

The central government created by Gustaf Vasa was not particularly sensitive to social welfare needs. The Swedish central state was not to become concerned about such issues until almost four hundred years later. Not until the society had become deeply changed by a comparatively late and fast industrialization. The first measures that were taken in the 19th century to handle social problems were taken at the local level, when Sweden was still an agrarian society. Typically the laws on poverty of these days dealt with questions such as which municipality should have to support migrant poor people. The role of the state was to regulate conflicts that could arise between different municipalities.

The sensitivity to social welfare needs, as it developed in the modern Swedish welfare state, dates back to the 1930's. Keynesian economic policy was introduced in the 1930's as an attempt to solve the economic crisis and to motivate social welfare expendi-

tures as a way of counteracting falling demand in times of crisis. At the same time, the social democratic party came into power and started its period of 44 years in government. This is the second root of our centralized response to social welfare.

This change in economic policy and political power became the foundation for the modern welfare state. The basis was laid in a compromise between labor and capital that allowed unions and employers to deal in a centralized way with labor relation disputes. Simply put, it might be said that capitalism was allowed to work on its own premises, with conflicts in industrial relations to be solved between parties without interference from the state. The state, however, would have much impact on the distribution of economic surplus thus created.

Ideologically, social democrats took on the role of guaranteeing material safety and providing good standards of living for everyone. The theme of equality was strong, but it was not formulated as ambition to strengthen the working class in the class struggle. Rather, the social democrats took on a paternalistic role, promising to create a good society for everyone. Typically, the most often proclaimed vision of the time was the idea of "folkhemmet" (the peoples' home). Swedish society should be like a good family home: characterized by equality, cooperation and helpfulness, by the breaking down of barriers between poor and rich, rulers and dependent, by a tone of equality and a common feeling of belonging.

The idea of society as a peoples' home mirrors the agrarian roots of social democratic thinking. It melds the socialist claim for equality through redistribution and collectivism with the agrarian tradition of charity and paternalism which underlies the moral duty to help.

This ideology combined with a reformist view of the state. Instead of viewing it in Marxists terms, as a means for the bourgeoisie oppression of the working class, Social Democrats sought to form the state as the father of the peoples' home. The Social Democrats took over the central state bureaucracy formed by Gustaf Vasa. The fact that a great part of the administration had a long tradition of implementing and administering political decisions in a non-political and technical way made this transformation much easier than it would probably have been in more politicized bureaucratic structure. Social reform came to be a systematic and rational decision-making process.

A strong central bureaucracy and the social democratic ideology are two roots of our centralized structure and social welfare. The whole answer, however, is not solely an effective administrative structure and egalitarian ideology. To get the system going there has to be some pressure in the form of interest articulation. This interest articulation from below is what I would call the third root of our present model.

The input to the system has been, not so much through divergence between political parties and through parliament, as through strong grass roots efforts and popular movements, often closely linked to the social democratic party. The claims of such organized movements were aggregated as much through a system of consultation and cooperation as through parliament. Typically, questions of disability were not put on the political agenda until the parents and the disabled themselves organized in the fifties and pressured for better services. Despite the emphasis on equality and the egalitarian vision of the peoples' home, handicapped people needed to articulate their own position within the system of organized pressure groups to get things going for them.

The tradition of centralized response thus rests on three different traditions:

The strong central state

The social reformism of social democracy

The influence of popular movements.

A consequence of these developments is that the role of charity, as well as of voluntary organizations, has been very limited. The "good state" more or less occupied the moral duty to help persons in need. Claims from the organizations of the disabled, for example, are formulated in terms of citizens' rights and it is a basic ideological consensus that such rights should be guaranteed and provided for by the state, not by private charity. Voluntary organizations may initiate new forms of services, but the understanding has been that the state or local government should take full responsibility in the long run.

The central response to social welfare, however, recognizes that most social services traditionally and still today are administered at a local, municipal level. The local administration, particularly during the last decades, has been very much governed by directives, guidelines, laws and resources decided at the central level.

In 1955, Sweden had essentially the same percentage of its budget dedicated to social welfare needs as other western industrialized nations. Today a much greater percentage of the budget is dedicated to social welfare needs. Can you give some insight into why this is true and what are the ramifications of this change?

During the 1950's, the basic social reforms were of a general nature, aimed at providing material safety for citizens who were in economic need because of unemployment, illness, or old age. This was done at approximately the same pace as in other industrialized nations.

In the 1960's, the ambitions raised. This was a decade of fast economic growth and bright forecasts for the future. Some politicians felt, given the rather tight net of social security offered, that the building of the welfare state had been accomplished. The structural changes, however, that created the economic growth also created new social problems. A new generation of radicalized politicians and researchers also pointed out that many inequities still remained. Surveys of the standard of living (in its broadest sense) were conducted that showed unequal distribution still remained in many areas. This was pointed out by different interest groups such as those organizations representing the interests of the disabled. The claims of these groups for further social reforms were often supported by the opinion of the general public.

The typical reform strategy of the time was piecemeal social engineering. The social engineer investigated the problems, searched for rational solutions and tried to solve them by means offered by the centralized structure. Committees were appointed to look into the problems and suggest how they could be solved. The means used were the central administrative ones. Special laws were passed on different issues, separate organizations were invented to deal with special problems, state grants were allocated for special use at the local level ("earmarked resources"). The state was, as some critics put it, trying to solve problems by throwing money at them.

The shift in ambitions meant that social reforms should not just aim at caring or curing manifest problems. Prevention became a goal in many areas of social reform. Education is a case in point. Earlier reforms had striven to abandon a parallel school system in favor of a comprehensive school that gave equal opportunity to everyone. The school reforms of the 1970's had much broader directives. The comprehensive school should also take responsibility for the leisure time activities of children. It should help prevent problems of individual children through flexibility and organizational reforms. Children with special needs should not be segregated, but resources allocated to support them within the ordinary school context.

The same kind of far-reaching preventive ambitions were proclaimed in health care and social services through the introduction of new legislation.

The case of the policy for disabled persons actually mirrors this trend quite well. At the beginning of the 1960's it became evident that those people with impairments and disabilities were lagging behind in benefiting from the welfare state. Largely as a response to pressures from the organizations of the disabled, several committees were appointed to look into the problems. The reforms implemented at this time covered areas such as housing: a law demanding that new buildings should be made accessible; transportation: the implementation of transport services in the municipalities supported by state grants; work: laws that oblige the employer to adapt work environments and only allows the employer to fire people on "objective grounds."

The goals of the organizations of the disabled during the 1970's were directed to show that a handicap was a relative phenomenon. Disabilities did not have to become handicaps. If the environment was adjusted to the capabilities of disabled people there would be no handicap. This argument suggested that general reforms to change the environment were the most effective ways of reducing problems for disabled people. The creation of "a society for all" was the adopted slogan. This kind of thinking corresponded to the general ambition of prevention at this time.

The reform strategy just described is a continuation of the centralized, social engineering approach that had characterized the 1950's and the beginning of the 1960's. During the 1970's this led to a great expansion of the public sector. In the beginning of the 1980's about one third of Sweden's GNP was consumed by the public sector and almost 40% of all employees were employed within this sector. What was once formulated as a vision of peoples' home was now turned into an idea of the "the strong society," a society that had the means and resources to help "weak" persons and disadvantaged groups.

It might be typical for the positive Swedish image of the state that we often make no distinction between "society" and "state." The "strong society" is actually the same thing as the "the strong state." Inequalities in the family (in the people's home) can be addressed by strengthening the power of the paternalistic father (that is, the state).

The high percentage of the budget devoted to social welfare can thus be seen as the result of using a traditional social engineering approach to reach higher ambitions. It is a means to turn the people's home into a strong society.

The economic health of a country will deeply influence its social conscience. Can you relate the economic health of Sweden and how it has had an impact on social policy during the last 30 years?

Sweden is a small country heavily dependent on foreign trade and thus on the international economic situation. The oil crisis caused gross imbalance in our foreign trade and the deficit of the state budget had to be filled in with loans from abroad. One reason for the continued expansion of the the public sector during the 1970's was that other industrialized nations probably responded to the economic crisis in a more direct way. In Sweden this reaction was delayed, not the least by the fact that our government, socialist as well as non-socialist, put so much emphasis on full employment. They refused to let unemployment grow by subsidizing industries and creating new public projects for support of the unemployed. By expanding public projects, people, who would otherwise be unemployed, could have a job and income. At the same time as the public sector was expanding, the number of persons in private industry diminished.

The financial crisis of the state, the political difficulties in steering, coordinating and, most of all, financing the growth of the public sector has led to retrenchment in the 1980's. The structural changes within the public sector intended to solve these problems can be summarized under the concept of decentralization. Municipalities and County Councils are given greater freedom from centrally issued regulations, special "earmarked" resources are abandoned, new legislation is of a "frame-work" kind, putting up ambitious goals for local authorities but leaving them great freedom and little money to be able to reach these goals.

I interpret this as the end of the era of the social engineer. The ambitious goals within social policy are not abandoned, but they are issued as goals for local authorities to strive to accomplish. There are, of course, some good reasons for this decentralization. I think, however, it deserves to be stressed that what is, in fact, delegated, is not so much freedom to decide and allocate resources. The state has rather delegated the conflict between needs and demands on one hand and scarce resources on the other hand to local authorities. The state, faced with the conflict between economic imbalance and high demand for public services decentralizes the conflict to be dealt with according to local standards. The good father of the people's home tells his family to keep the ambitions up, but gives them no means for reaching their ambitions.

The changed economic situation and the changing structure within our public sector also has consequences for our way of conceptualizing and dealing with the problems of disabled people. During the era of the ambitious social engineer, philosophies and principles were formulated as guidelines for social reform. I am thinking of the principle of integration, the principle of normalization and their perspective that handicap is a relative condition that is created by environmental circumstances. These principles are still very much explicit goals of our policy for the disabled. As the economic situation changes, however, so does the way these principles are applied. They get stripped of their ambitious concrete meaning and are used to diffuse guidelines for services. Many people pay lip-service to these principles, but don't understand the practical consequences of their enactment.

Let me take the principle of integration to illustrate my point. Integration was formulated in opposition to the kind of segregative measures that traditionally prevailed in this area: institutions, segregated schools, special classes and so. When first formulated it was tied to a vision of the disabled being socially integrated and taking part on an equal basis in the collective life of society. It was an ambitious principle. In the hands of the social engineer it would mean releasing resources for services and support that would make it possible for a disabled person to live in the mainstream of society.

The principle of integration tends to lose its connection to the ambitious goal of social integration with the present economic retrenchment and structural changes in the public sector. Rather, integration has come to mean physical placement of a disabled person among others. Instead of motivating ambitious measures to facilitate social integration, it is used to motivate *laissez-faire*. From the critique of segregation, the conclusion is drawn that special resources of any kind have potential segregating effects and therefore should be dismissed. The handicapped child is placed in ordinary environments, but left with little support to deal with the problems related to his/her disability. The principle of integration is thus drained of its original ambitious content and used as a means to define the problems away.

The same process of adaptation to economic restrictions can be seen in the use of the principle of normalization. Originally intended to articulate the rights of a disabled person to be treated as an equal citizen in a normal environment, it nowadays is sometimes used to deny that person the support he needs to be able to handle problems in the so called normal environment. Many parents of retarded children in Sweden are reporting that services are being denied on the grounds that they are "unnatural." The ambitious principles of the optimistic 1960's are used in the stagnation of the 1980's to make the special needs of disabled persons invisible.

The economic health of a nation does indeed tend to influence the social conscience of a nation. It is not, however, as deterministic or fatalistic as it may sound. There are many degrees of freedom that can be used by pressure groups and organizations to promote the basic ideas of solidarity and appeal to the values that many Swedes grew up with during the 1960's. The process requires careful analysis of both the present situation and future trends in order to make the appropriate demands on the system. After all yesterday's claims, for example, for more normalization and integration, may not be quite adequate to meet the situation today.

Do you believe it is a responsibility of the government, whether local or federal, to act as a social engineer to correct what is perceived as being as "inequality" in the system?

Yes. I think most Swedes would immediately answer this question that way. Some of us may even feel that this is so evident that it feels strange to be confronted with the question.

In our earlier discussions I have stressed the influence of social democratic ideology in explaining the response to social welfare in Sweden. But confronted with this question I realize that the basic assumption about the responsibility of the state is shared among most Swedes regardless of political opinion.

It is true, however, that the rapid growth of the public sector during the 1970's and the financial crisis has led to some criticism. The basic theme of the criticism is that the state is becoming too much involved in ordinary people's lives, interfering in matters that are better dealt with within the private sphere. This argument has been voiced both from the right and from the left.

From the right, it is usually put in the framework of neo-liberal economic thinking. The rationality of political decision making and the basic ideological commitment among pol-

iticians and bureaucrats is questioned. True to neoclassical economic thinking, self-interest is postulated as the prime motivator for the actions of human beings. Self-interests, the argument goes, can not be coordinated and social order established as effectively by politics as by the market. Critiques from the conservative party, therefore, advocate breaking up the monopoly of the public sector in health and social welfare and introducing privatized market-based organizations.

Critique from the left usually questions the social democratic conception of the state as being neutral, standing above class struggle. It emphasizes the dangers of the state interfering too much in what is called "civil society." The civil society is seen as an arena for exchange of ideas and a guarantee for freedom of expression. The "civil society", it is argued, is threatened by state interventions that goes too far in taking over functions such as socialization, reproduction and caring responsibilities from the private arena. The state is not seen as the good father but as a potential means for the destruction of spontaneous and collective reciprocal support with the working class.

Ideologically, the present trend towards de-bureaucratization and decentralization owes more to the left wing critique than to the right. I believe, however, it is fair to say that in practical politics no one really questions the basic assumption that government has a responsibility to act in order to diminish inequalities.

At least this is the case when it comes to questions of disability and handicap. Unlike other social problems, such as alcohol abuse and drug addiction, disability is something that you can not hold a person morally responsible for acquiring. It is not a problem that, in the public view, is tied to social class. It is a kind of problem that transcends ideological conflicts on moral responsibility.

In a way, therefore, disability and its consequences in terms of disadvantages and handicaps, is an example of the kind of inequity that everyone agrees should be compensated for by government intervention. Political discussions on these issues concerns the means: how it should be done rather than if it should be done. The well-meaning intentions and benevolent attitudes in this area transcend to a great extent, political boundaries.

What do you think are the social policy trends based on political and economic projections for the future?

Let me try to narrow this question by focusing it on the policies for the disabled instead of social policy in general.

There is a general consensus among political parties and the organizations of the disabled on the policy goals in this area. Equality of access, integration, normalization and general solutions rather than special measures are the most important goals. These

goals are to be reached, or at least approached, in times of economic retrenchment through decentralization in the public sector.

This combination of ambitious goals, decentralization and agreement on the necessity of cutting down public expenditures will create problems and tensions in the near future.

Let me point out some of these problems.

Geographical inequity is becoming a problem. One of the arguments for letting local authorities make decisions on their own is that they are close to the problems, and therefore, are best suited to decide on how to solve them. Some of the organizations of the disabled have warned against this development because it results in greater differences between municipalities. Services that are provided in one area might be difficult to get in another area.

The National Associations of the Handicapped recently published a report that tends to support this skepticism regarding the effects of decentralization. The survey showed that only 18% of the municipalities lived up to the requirements in the Social Services Act that they should inform disabled people of their rights. Less than half of the municipalities had investigated the needs in their area and only 4% had made plans to provide activities and employment for people with disabilities.

The municipalities that did best in this survey were large municipalities with a high percentage of employment in the public sector and comparatively active local organizations of the handicapped.

A second problem to be faced in the near future is a tendency among local decision makers to ignore the needs of the disabled when given freedom to allocate resources.

A feature of the present trend towards decentralization is to give local authorities freedom in deciding how to use state grants. This change has perhaps been most obvious in the educational field. Several previously earmarked resources for special support to disabled pupils have been abolished in favor of a system where grants are placed at the free disposal of municipalities. Centrally issued goals, however, are quite explicit in stating that grants should be used to satisfy the needs of pupils requesting special support.

Evaluative research has shown that this goal has not really been reached. Many municipalities and school management districts evidently prefer to use the free resources for general reforms, such as reduction in the number of pupils in each class, rather than for specific measures aimed at supporting pupils requiring special support.

A third kind of problem is the ideological development that I touched upon in our discussions about the impact of Sweden's economic health on the delivery of services. The ideological principles such as integration and normalization tend to be used in a way that rationalizes and legitimatizes cutting down of support for disabled people and their families rather than for articulation of their needs. These principles were once formulated to motivate desegregation by trying to point out the fact that disabled people are just like anybody else. They have the same needs and the same rights as other citizens. The ambition to de-mystify the consequences of disability is, however, used today to overshadow the fact that disability might have dramatic consequences for the disabled person and his family. I think there is a need for formulating new ideological principles in this area, principles that help to articulate rather than to hide the need for special support.

Traditionally, the safeguard against abuse of the rights of the disabled at the local level has been strong state bureaucracies. This "control from above" will not work in the fu-

ture. The safeguard against the dangers I have pointed out have to be sought elsewhere.

One such safeguard will be the organizations of the disabled. They have been organized to respond to the traditional centralized system and are strong at the central level. Such organizations are quite influential when it comes to affecting decisions that are made in Stockholm, but the present changes will mean they must get better organized locally. This re-orientation is on its way. Much of the outcome of services for the disabled in the future will depend on the ability of the organizations to handle this change of strategy.

Another safeguard will be the right of parents and the disabled to appeal to administrative courts for getting the services they want. This is a possibility that has been opened up in recent legislation. The law for services to mentally retarded people clearly illustrates this point. In the old law, county councils were obliged to provide certain kinds of special services. They had to answer to the National Board of Social Affairs. In the new law, services should only be provided if requested by the disabled person and/or his or her parents. If they are denied services that should be provided according to the law they can appeal to court to get it. Experiences from this rather new kind of "control from below" is, so far, rather limited.

In the future, therefore, much of the outcome of present changes and restrictions will depend on how well organizations of disabled as well as individual persons and their families can use these instruments for controlling local authorities.

I realize that what I have stressed as a change in the system and the control mechanisms might sound familiar and self-evident to an American public, who is accustomed to using the courts in this way. For many Swedes, however, there is a fear that these new system changes will not work. This fear can be best understood by realizing the Swedish philosophy in social politics goes a long way to insure the rights of "weak" persons: persons who, due to different circumstances, have problems in articulating their interests and defending their rights. The good father of the people's home has an obligation to care also for the disabled person who doesn't have the resources to fight local authorities in courts. There might be a good future in the new system for the "heroic disabled," persons with disabilities who are better equipped to fight for their own interests. The problem of the future might be, however, to find the balancing point where this is combined with guarantees that will secure the rights also for those people with disabilities who do not have the resources to fight that way.

Agneta Hellström

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How is it determined what services are needed and should be provided?

The responsibilities for social welfare programs are divided among three administrative levels: national government, municipalities (which are local units), and county councils (which are regional units).

The national government is responsible for laws, ordinances and supervisory functions and also for direct grants aimed at achieving uniformity of accessibility. This applies, for instance, to the social insurance system and educational programs available to all citizens, regardless of where they live. There are also a number of programs and grants directed to certain groups such as families with children and disabled persons that are regulated by national laws and administered by the state. Some examples of national programs that provide financial assistance include:

Child Allowance for all children from birth until the age of 16,

National Housing Allowance for families with children,

Parental Insurance System that gives financial compensation to all parents when they stay at home to take care of their children.

For disabled children and their families there are, however, additional benefits from the state such as the Child Care Allowance and Home Adjustment Grant. An individual review is made to determine the extent of the child's handicap and the needs of the family. The allowance is not dependent on the family's income, but on the child's need.

The national government is responsible for the laws that regulate social services, education and health services and medical care. It is the responsibility of the local authorities to provide the services mandated by national legislation.

The services that should be provided according to the laws are described in rather general and goal-oriented terms. Great freedom is given to local authorities, municipalities and county councils to design their own programs. An exception to this principle is the Special Act which specifically describes the rights of people with mental retardation.

In recent years the independence of the local authorities has increased. The national government, nevertheless, still has great influence, not only through laws but also through grants, national programs and recommendations. There is, however, a mutual dependence and close cooperation between the different administrative levels.

There are several mandated national programs that include preschool, elementary and secondary education, as well as education for the disabled. In all these programs, the need for and the right to special support for disabled children and their families is strongly emphasized. Supervision and overall planning are provided by the national authorities.

The municipal government is responsible for basic social services, primary and secon-

dary education, culture, leisure time activities, technical services and other basic services for its inhabitants. On the local authority level there are 284 municipalities.

The right to receive aid in connection with various social welfare problems is mandated in the Social Service Act. Among other things, this law regulates preschool education, child care, services to the disabled, care of the elderly and of people with different kinds of problems. There is a special section in the law that emphasizes the rights of people with disabilities to live as normal a life as possible. Another section gives placement priority to disabled children entering preschool and leisure time centers. This same section defines the right of these children to obtain the support necessary to make their mainstream experience meaningful. Other services which can be provided for families with disabled children, according to this law, include: relief-service through child minders or so called support families, home help, foster homes, and transportation services.

The local authorities decide what services should be provided. Local planning is made as well as investigations of actual needs among the inhabitants. Some of the sections in the act are more binding for the municipality than others. The individual is not necessarily guaranteed the services described. The need is examined for each individual case. It is said, however, that any person who has the need for a certain assistance should be entitled to it. Services should be provided in close cooperation with the person concerned and with great respect for their wishes. A person who is not satisfied with the decision of the municipal social welfare committee may take the matter to the county administrative court.

In Sweden there are 25 county councils, which are wider local units than municipalities. The county councils are predominantly responsible for providing health services and medical care according to the Act of Health and Medical Care. This law regulates public preventative health services as well as hospital care.

The Act of Health and Medical Care is goal oriented and more general than the Social Security Act. The Act of Health and Medical Care clearly says that services and treatments should be given with great respect for the patient's wishes. Under this law disabled children and their families have equal rights with other inhabitants to receive health services and medical care related to their special needs. Unlike the Social Security Act, the Act of Health and Medical Care does not include the right to appeal a decision except for cases where it is obvious that the prescribed treatment is injurious to the patient.

In addition to these responsibilities, the county councils provide habilitation services for disabled children. In the past these services were organized according to the disability concerned. Many counties, however, have now coordinated their different habilitation programs to form comprehensive service models available to all children with special needs and their families. The habilitation programs include medical, educational, psychological and curative support for the child and its family. Habilitation is provided by mobile therapeutic teams with different professionals working on a district level close to the child's daily environment.

Habilitation programs should be available to every disabled child and family who needs them. There should be no necessity to have a diagnosis as a condition to access these services. The need alone should be reason enough.

There is, however, a complication in the present law which discriminates according to the disability of the child. Only for the child with mental retardation is there a guaranteed right, by law, to habilitation services. Through the special law for people with mental retardation, rights are clearly specified. It includes an entitlement by families to take their dissatisfactions with services to the county administrative court. This lack of equality between different disability groups is, of course, unacceptable. It is now being reviewed and will be shortly subject to legislative change from the national government.

The local habilitation program for a child is decided in close collaboration between the parents and the different professionals who are members of the therapeutic professional team. These members may include physicians, physiotherapists, speech therapists, psychologists, occupational therapists, social workers and special education teachers. To avoid too many people around the family, however, one member of the team is chosen to coordinate services and be the primary contact with the parents.

All children and their families do not obtain the habilitation services to which they are entitled. The limits of habilitation services are generally due to a shortage of resources, especially for physiotherapy. Today it is common for parents to tell what services they feel are needed for their child. Formerly, "specialists" played the dominant role in designing what was best for the child.

The county councils act just like the municipalities of the local government. They also decide what services are to be given and how the resources should be distributed as they relate to actual needs and predetermined objectives. It is a present trend that many issues, formerly the responsibility of the county councils, are being transferred to the municipalities according to the principles of normalization and integration for the disabled. This process is important, but it also creates confusion in defining the areas of responsibility for municipalities and county councils. The consequences for the family can be very severe when both these local authorities say that it is the duty of the other to provide a particular service. It is, however, the ultimate responsibility of the municipality to provide care.

How is program effectiveness evaluated?

Sweden actually has no strong tradition of evaluating social welfare programs. I think there is a great difference between our countries in this regard. Our social welfare ideology is very much based on the view that social welfare programs should be available to everyone as a basic human right. When disabled children are integrated in regular pre-schools and schools, for example, this is looked upon as a question of equality and social rights. There are no conditions set on it. Nor are there expectations that the children should become "better" or that the experience be proved "useful" in some special way. It is just a matter of their equal right to take part and be in the fellowship together with "normal" children. Of course we want their stay to be as meaningful and stimulating as possible. We are aware of the fact that special efforts are required to reach this aim. Support, such as personal assistance, individualized training and technical aids are often necessary.

In fact, there have been efforts made to evaluate integration of disabled children in pre-school and school. The question asked in these studies has often been, "Has integration been successful?"

The results show that the answer is very dependent on the variables of the question. What are the expectations for integration concerning participation, fellowship, learning and well-being of the child? What is the definition of success and how is it measured? The results of the evaluations clearly demonstrate that expectations must be realistic. The handicap can never be denied and is always a limitation that can cause difficulties for the child in learning, playing and social situations. Rather than asking ourselves if integration is good, we should ask how to make it better. Here, research and development projects of an action research nature could be productive.

There has been little evaluation concerning habilitation, special support and training for disabled children. The nature of the research studies has most often been whether the parents are satisfied with the services provided. A formidable challenge, however, would be to measure the effects of the total habilitation program on the child and family.

The aim would be to measure the programs' impact on the quality of life, human development, well-being and long term character. These are not easy qualities to measure. Also, studies that compare different habilitation methods would be desirable.

I think it is important to remember that in Sweden we do not choose our aims and methods of habilitation due to measurable and visible results, but rather due to what we believe we can bring to the development and well-being of the child. The most important ingredient is what happens inside the child. Such goals do not have to be in opposition to the demands of effectiveness.

On the national level today there is a trend to ask for analytical results of program design. An example is the evaluation of the government program for the disabled which has recently been undertaken.

What are today's major issues in caring for children with disabilities?

One area in which I believe there are definite deficiencies is the accessibility of practical home service help and relief for families. The praise worthy objective of enabling every child to grow up in his/her own family circle may lead to an unreasonable burden on the child's parents, in most cases the mother, but also the father, brothers and sisters.

Parents in the near future may find themselves unable to cope with the situation and we will have a new trend in which residential institutions are in demand again. Financial allowances for families are helpful, but by no means compensate for the lack of freedom, risk of isolation, inability of one parent to work and anxieties about the future. I am thinking particularly of parents of multiply disabled children. Parents must be offered better facilities for temporary relief in the form of child minders, home helpers, so-called support families, and short term houses that provide temporary care in a homelike environment.

Another area is the situation in preschools and schools. If integration is to lead to a real sense of belonging, the staff and teachers need much more information and training concerning the special needs of the children. It is also necessary to provide psychological support to the staff to help them cope with feelings of insufficiency, insecurity, fear, pity and maybe dislike that working with disabled children can evoke.

The leisure sector can be a problem for the child with disabilities. Comradeship often is based on one's ability to get about freely, something that can be difficult for a child with disabilities. A strong wish would be for hobby clubs and youth organizations to take more of an initiative to invite disabled youngsters into their activities and make it possible for them to participate successfully.

Today it is strongly emphasized that disabled children and their families are entitled to obtain basic support and assistance within society's regular services such as preschool, regular education, social services, primary health and so on. Formerly, these children and families would have been forced to apply to special programs, organizations and institutions to receive services. Although these are positive developments and much progress has been made, there are still problems to be solved and challenges to be met.

A close collaboration between specialists and staff within the regular services is necessary. This has also proved to be much more complicated than we originally predicted. Difficulties in collaboration and cooperation are to a large extent due to differences in points of view and also due to the fact that the specialists sometimes have a tendency to distrust regular services staff. It is not unusual to find that specialists have difficulty letting go of the "overall responsibility" of children they have worked closely with over a period of time.

What are the new influences and trends that will affect the way services are delivered?

In addition to the many issues we have talked about in this interview, I personally find one of great interest and importance. As a consequence of making the environment and the whole situation around the disabled child and his/her family more normal, I believe that both children and parents will meet much more "normal" attitudes and expectations. Instead of being "patients" and "clients" they can now be treated as "fellow beings" on an equal level. The child will be primarily looked upon as a child, not a disabled child, the parents accepted as parents like all other parents, not as disabled parents in a disabled family.

We shall not forget that there has been an enormous dominance and influence from the specialists in this field. The specialist's word, especially the physician's, has been "law" and the parents have not had much influence over the care provided. Somebody else has always told them what is better for them and for their child, even though the opinion of what is right has changed from one time to another.

Today parents have more self-confidence. They begin to trust their own ability to determine what is best for their child and family. An increasing tendency is for parents to demand respect for their competency as parents since they know their child best. They do not want to be their child's teacher or therapist... nor do they want to be regarded as self-sacrificing heroes whom people both admire and pity. They just want to be parents.

This is the revolution going on in Sweden that will influence all future services to children and families.

Ann Turnbull

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As both a professional in the field of special education and the mother of a son with special needs, you have a unique vantage point in looking at families who have a member with a disability. Can you, Ann, describe how these families, in particular, have been affected by the evolution of social policy in the United States?

Expectations for family patterns in families with a member with a disability have evolved overtime. Generally, however, from the 1900's through the 1950's a predominate expectation was that families should institutionalize their child very early in the child's life to "protect" the other family members, including siblings, and the parents' marriage from strain.

Government policy emphasized substitute, rather than supportive, family assistance. That is, the family could institutionalize their child and turn over practically all parental responsibilities and rights. Only minimal services, such as respite care and case management, were provided to help families maintain their member within the family and cause undue strain.

Services that have developed since the 1950's have largely been initiated through parental advocacy. The trend in the USA has been for families to be the "change agents" by investing tremendous time in holding the system accountable for serving their children. The governmental role has been in responding to parental pressure rather than in actively initiating efforts to insure equal opportunity. A key positive element, however, has been the willingness of policy makers to listen to parents and to respond in a bipartisan fashion. In fact, it is clear that parental advocacy has generally been more effective than professional advocacy because of the view that parents speak from "24-hour reality."

The pendulum has swung drastically from expecting families to institutionalize their member with a disability to now expecting families to provide family care over the lifetime with or without support. The fact that monumental waiting lists exist for residential or employment services for adults is not a consideration in expecting families to embrace community living. Thus, values related to family roles have changed drastically over the twentieth century from institutionalization to deinstitutionalization and from custodial care to independent living. Despite this change in values, families have typically not been provided the support services to implement the new values. For example, it costs an average of \$50,000 per year for the institutionalization of one person with a severe disability. Although the government is willing to underwrite this cost, the family of that same person is usually offered little to no support to provide home care. There are many elderly parents still providing care for their middle-aged sons and daughters with a disability. They have grave concerns about what will happen when they die; yet, this fundamental need for future planning is currently not being addressed. Thus, a major gap exists between expectations for families and support to meet those expectations.

A most encouraging development is the passage of new legislation to provide early intervention to infants and toddlers with special needs and their families. This legislation for the first time requires services that are responsive to the family's strengths and needs associated with their child's development. The association with the child's developmental needs is a key consideration. The philosophy is primarily aimed at supporting the family so they can best help the child and not supporting them related to family priorities, such as adequate income or housing, that might not be directly tied to the child's needs.

Family support in the US slowly evolves over time. Thus, the beginning efforts to support families during early intervention related to developmental needs will likely evolve in the future to greater family support at later life span stages and with needs other than child development.

Do you feel these same factors have influenced the type of services provided to children with special needs?

As stated above, the trend for substitute rather than supportive care has definitely influenced services, primarily in allocating the majority of resources toward institutional rather than community care. Major legislation is being debated that will reverse that trend and drastically phase down the institutional services by the end of this century. The major opposition to this legislation includes institutional service providers who fear job loss and families whose members have been institutionalized for significant periods of time. Gradually, however, momentum is building for the redirection of funds. This redirection would constitute the implementation of policy and services to support families to be successful rather than to substitute for family care.

Other trends in service include:

a) Services have generally been fragmented: education and health; preschool, school-aged, and adult; specialized and generic. The fundamental issue is that services have been developed piecemeal and in response to special interest groups. Also the US style of gradualism has resulted in "trying to get a little bit more each year." There has been no long-range plan for a federal, state, and local partnership in developing comprehensive family support services. Such an effort may be able to be undertaken during the next five years. Also, there is currently major emphasis on transitional planning to insure successful movement from one program to another. The need for such planning is greatly increased because of the fragmentation of services. For example, many secondary teachers have not visited residential or employment sites in their communities and thus do not know the specific skills that will best insure success in those adult settings. Transitional planning is a key component of comprehensive services, but the major US challenge is to develop a coordinated services system that insures continuity.

b) When family services have been offered, typically these services have been directed to mothers with the assumption that mothers represent family interests. Families have generally been conceptualized in traditional patterns with little attention given to the diverse composition of many family units. The new early intervention legislation uses the word, "family" rather than "parent" and has been a catalyst for recognizing that families should define who their members are rather than having service providers make traditional assumptions. There is a beginning recognition of the needs of fathers, siblings,

grandparents, extended families and caregivers such as family friends unrelated by blood or marriage but heavily involved with the member with special needs.

Do you think that decisions made by a centralized government/bureaucracy come as a result or by-product of already existing trends or do the decisions in themselves create social change and new trends?

The formulation of governmental policy related to disability in the US has been a combination of the influence of existing trends and the creation of social change. A case in point was the passage of P.L. 94-142 in 1975. Several major trends influence the passage of this major educational "bill of rights" including civil rights gains in the area of race, lawsuits brought in many states asserting the right to education for students with disabilities, state legislation resulting from lawsuits, parental advocacy through organized groups, and professional advocacy. On the other hand, P.L. 94-142 was the precursor for legislation to extend educational opportunities to children from birth-5 and 18-22 (age 26 in Michigan). It also was a catalyst for transitional planning, funding of parent training and information centers, supportive employment initiatives, deinstitutionalization, and heightened expectations for community integration for people with disabilities. It is a good example of the incremental approach to social change in the US policy, generally, as both a consequence and an antecedent to other related developments.

What do you think are the pros and cons of this incremental approach to policy development?

The major pro in the incremental approach is that a political party is not able to make sweeping changes or reversals that might ultimately hurt the field (as the Reagan administration attempted in trying to deregulate P.L. 94-142). Another pro from a conservative fiscal perspective is that monumental new funding is generally not required since incremental and phase-in changes are typically required rather than more drastic ones.

The major con is that a system of services can really never be fully planned and implemented. The piecemeal, one-step-at-a-time, approach means that we sometimes lose the concept of the forest while concentrating policy attention on the trees.

Can you look into your crystal ball and give your vision of the future for families who have a member with a disability?

With the new early childhood legislation, I think we are moving into an era that will be more family-centered than exclusively child-centered. Services will be conceptualized more from the perspective of helping the family collectively to meet its needs, rather than individually focusing on the child only or child and mother only. This approach will be planned to coincide with the family's strengths and not just respond to their needs.

From this early family focus, one result is likely to be greater expectations for the child to grow up in the family and be integrated into the community as an adult. Increasing-

ly, as families have an opportunity to know about employment and independent living that can be characterized by dignity and relationships with people with a disability, I think there will be a stronger vision to make the potential for this lifestyle a reality. Thus, families and professionals are likely to focus more on integrated options for school and recreation and realize that separate and specialized settings generally prepare children for a separate and specialized life.

Because of an increased emphasis on integration, there is likely to be a greater use of generic services such as neighborhood schools, community recreation, typical health care systems and vocational educational options. A major issue will become the planning and funding of services that bridge the specialized and generic sectors. A promising development is the formation of a State Interagency Coordinating Council federally mandated to include parents, public or private service providers, representatives from the state legislature, persons representing personnel preparation, and other people determined by the Governor to be appropriate. This council is required to advise and assist the state in providing early intervention and early childhood services. A future trend might be to continue statewide, interagency planning for services across the life span.

In the past, children and adults with disabilities have had little voice in decisions that affect them. It has been presumed that parents always represent the best interest of their children and that it is appropriate for parents to continue to speak for their sons or daughters with a disability, even when that person is an adult. There is a growing awareness that much more attention needs to be directed at insuring that children, youths, and adults learn to express their preferences and make choices consistent with those preferences. In the future, there is likely to be an increased emphasis on self-advocacy through greater instruction in decision-making skills and greater opportunities for involvement in micro and macro formulation of policy.

Ultimately, the reversal will be made from substitute to supportive family care. Federal legislation will direct funding from institutional to family settings and families will have greater access to services such as home health aides, respite care, transportation, and case management. If these services are funded through family vouchers, there will be an increased incentive for the system to be responsive to families since the purchasing power will be in the hands of families.

With the move toward family and community living, there will be a trend to downgrade the size of service units. For example, the "herd mentality" of congregating people with disabilities into large residential programs or sheltered workshops will gradually be replaced with adhering to principles of natural proportion in providing services. Thus, group homes are likely to have six or less people living together and to move to the point of replacing "group homes" with "homes" where living patterns are more similar to those of the general population.

Finally, the key strategy for influencing policy in the US is through the organized efforts of advocates. The trend has been the development of special interest groups based on type and level of disability, age group, philosophy, and service needs. There is a beginning trend for collective action across groups on issues of shared concern. For example, seven special organizations in the field of mental retardation (representing parents, service providers, personnel trainers, and researcher have merged efforts to form a Consortium on Research in Mental Retardation. This Consortium speaks with a single voice

concerning the funding levels, topics, and processes of research relevant to mental retardation. Whereas in the past these groups have tended to work individually or sometimes even competitively, there is growing affirmation that unity is the most fruitful strategy on topics of shared interest. This trend is likely to continue and to even expand to coalitions of the disability, child, and elderly constituencies on topics related to family dependency such as home care health and access to health insurance.



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